

# Uncertainty in Adolescents and Young Adults With Cancer

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**Purpose/Objectives:** To describe uncertainty in three groups of adolescents and young adults with cancer at specific times in their cancer experience: newly diagnosed, diagnosed one to four years, and diagnosed five or more years.

**Design:** Descriptive, cross-sectional, comparative.

**Setting:** Six pediatric oncology centers in North America.

**Sample:** 193 adolescents and young adult cancer survivors aged 11–22 years, able to read English, with no central nervous system disease.

**Methods:** A booklet of questionnaires was completed during a clinic visit or hospitalization. Uncertainty was measured using Mishel's Uncertainty in Illness Scale.

**Main Research Variables:** Uncertainty and time since diagnosis.

**Findings:** No significant differences were found in the overall level of uncertainty among the three time-since-diagnosis groups; however, analysis of variance on individual items detected significant group differences for 8 of the 33 items. Newly diagnosed survivors had significantly higher uncertainty for future pain, the unpredictable illness course, staff responsibilities, and concerns about when they would be able to care for themselves. Survivors five or more years from diagnosis had significantly higher uncertainty related to knowing what was wrong, and they had more unanswered questions and higher uncertainty compared to the two other groups about the probability of successful treatment. All of the survivors had high uncertainty about the multiple meanings of communication from doctors.

**Conclusions:** The overall level of uncertainty remained unchanged across the survivorship continuum, but differences existed in specific concerns.

**Implications for Nursing:** Uncertainty is important to consider far beyond the treatment period, particularly assessment of information needs and acknowledgment of inherent uncertainty throughout cancer survivorship.

Advances in the treatment of pediatric cancer have dramatically improved survival rates to 78% at the five-year point (Institute of Medicine, 2003; National Cancer Policy Board, 2003), but the outcome for individual children and adolescents remains unpredictable. Cancer now is considered a chronic illness with no definitive end point. Uncertainty throughout the cancer experience long has been identified as a significant aspect of pediatric cancer and a major concern of adolescent and young adult cancer survivors (Bearison & Pacifici, 1984; Novakovic et al., 1996; Parry, 2003; Prouty, Ward-Smith, & Hutto, 2006).

Studies of uncertainty during illness experiences such as cancer have shown that high levels of uncertainty create a stress response (Barron, 2000; Mishel, 1981), which, in turn, results in defensive coping (Haase, 2004), anxiety, fear,

## Key Points . . .

- Uncertainty related to cancer is an understudied but important concern for adolescent and young adult survivors of childhood cancer.
- Overall uncertainty levels did not diminish from the time of diagnosis throughout long-term survivorship for adolescents and young adults with cancer.
- Overall uncertainty levels remain high throughout the cancer experience, so healthcare providers should continue to assess the specific focus of uncertainty across the survivorship continuum.

and distress (Edwards & Clarke, 2004; Friedman, Freyer, & Levitt, 2006). Research with adults indicates that high uncertainty is linked with problems in processing new information (Gaberson, 1995; Mishel, 1990), predicting outcomes, and adapting to cancer diagnosis (Mishel, 1990). Most research in the area has been conducted in the adult population and has focused primarily on the early stages of survivorship. The current study seeks to address the gap in the understanding of uncertainty across the multiple stages of survivorship, from diagnosis through several years of treatment, in adolescent and young adult survivors.

The purpose of this cross-sectional, secondary analysis study was to describe uncertainty in three time-since-diagnosis groups of adolescents and young adults with cancer: newly diagnosed, diagnosed one to four years, and diagnosed five or more years. The time-since-diagnosis groups were chosen to reflect the different stages in the cancer experience. The term "cancer survivor" is used to describe an individual from diagnosis through the remainder of his or her life (Centers for Disease Control and Prevention, 2004). Survivorship has been divided into a series of stages: acute, extended, and permanent (Mullan, 1985). The acute stage represents the initial

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